

Union Calendar No. 235

110TH CONGRESS
1ST SESSION

H. R. 1727

[Report No. 110-378]

To enhance and further research into paralysis and to improve rehabilitation and the quality of life for persons living with paralysis and other physical disabilities, and for other purposes.

IN THE HOUSE OF REPRESENTATIVES

MARCH 28, 2007

Ms. BALDWIN (for herself, Mrs. BONO, Mr. LANGEVIN, and Mr. BILIRAKIS) introduced the following bill; which was referred to the Committee on Energy and Commerce

OCTOBER 15, 2007

Additional sponsors: Ms. SCHAKOWSKY, Mr. FRANK of Massachusetts, Mr. MARKEY, Mr. BUTTERFIELD, Mr. WAXMAN, Mr. MORAN of Virginia, Mr. McNULTY, Mr. STARK, Ms. ESHOO, Mr. GENE GREEN of Texas, Mr. DELAHUNT, Mr. HOLDEN, Mr. McHUGH, Mrs. EMERSON, Mr. RANGEL, Mr. MEEHAN, Mr. RAMSTAD, Mr. CAPUANO, Mr. DENT, Mr. TERRY, Mr. TIERNEY, Mr. WALZ of Minnesota, Mr. KENNEDY, Mr. YARMUTH, Mr. GRIJALVA, Mr. GILCHREST, Mr. WEXLER, Ms. DEGETTE, Mr. MCGOVERN, Ms. SUTTON, Mr. PAYNE, Mr. WELCH of Vermont, Mr. WYNN, Mr. HONDA, Mr. WALDEN of Oregon, Mr. LAMPSON, Mr. NEAL of Massachusetts, Mr. ENGEL, Mrs. LOWEY, Mr. TOWNS, Mr. OLVER, Mr. ALLEN, Mr. YOUNG of Florida, Mrs. MALONEY of New York, Ms. MCCOLLUM of Minnesota, Ms. GINNY BROWN-WAITE of Florida, Mr. MARSHALL, Ms. KAPTUR, Ms. HERSETH SANDLIN, Mr. PATRICK MURPHY of Pennsylvania, Mr. TIBERI, Mr. WOLF, Ms. LEE, Mr. HINCHEY, Mr. LYNCH, Mr. BERMAN, Mrs. CAPPS, Ms. HARMAN, Mrs. NAPOLITANO, Mr. ALTMIRE, Mr. KILDEE, Mrs. MCCARTHY of New York, Mr. INSLEE, Mr. GORDON of Tennessee, and Ms. PRYCE of Ohio

OCTOBER 15, 2007

Reported with an amendment, committed to the Committee of the Whole House on the State of the Union, and ordered to be printed

[Strike out all after the enacting clause and insert the part printed in italic]

[For text of introduced bill, see copy of bill as introduced on March 28, 2007]

A BILL

To enhance and further research into paralysis and to improve rehabilitation and the quality of life for persons living with paralysis and other physical disabilities, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
 2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 *This Act may be cited as the “Christopher and Dana*
 5 *Reeve Paralysis Act”.*

6 **SEC. 2. TABLE OF CONTENTS.**

Sec. 1. Short title.

Sec. 2. Table of contents.

TITLE I—PARALYSIS RESEARCH

Sec. 101. Activities of the National Institutes of Health with respect to research on paralysis.

TITLE II—PARALYSIS REHABILITATION RESEARCH AND CARE

Sec. 201. Activities of the National Institutes of Health with respect to research with implications for enhancing daily function for persons with paralysis.

TITLE III—IMPROVING QUALITY OF LIFE FOR PERSONS WITH PARALYSIS AND OTHER PHYSICAL DISABILITIES

Sec. 301. Programs to improve quality of life for persons with paralysis and other physical disabilities.

1 ***TITLE I—PARALYSIS RESEARCH***

2 ***SEC. 101. ACTIVITIES OF THE NATIONAL INSTITUTES OF***
3 ***HEALTH WITH RESPECT TO RESEARCH ON PA-***
4 ***RALYSIS.***

5 (a) *COORDINATION.*—*The Director of the National In-*
6 *stitutes of Health (referred to in this Act as the “Director”),*
7 *pursuant to the general authority of the Director, may de-*
8 *velop mechanisms to coordinate the paralysis research and*
9 *rehabilitation activities of the Institutes and Centers of the*
10 *National Institutes of Health in order to further advance*
11 *such activities and avoid duplication of activities.*

12 (b) *CHRISTOPHER AND DANA REEVE PARALYSIS RE-*
13 *SEARCH CONSORTIA.*—

14 (1) *IN GENERAL.*—*The Director may make*
15 *awards of grants to public or private entities to pay*
16 *all or part of the cost of planning, establishing, im-*
17 *proving, and providing basic operating support for*
18 *consortia in paralysis research. The Director shall*
19 *designate each consortium funded through such grants*
20 *as a Christopher and Dana Reeve Paralysis Research*
21 *Consortium.*

22 (2) *RESEARCH.*—*Each consortium under para-*
23 *graph (1)—*

24 (A) *may conduct basic, translational, and*
25 *clinical paralysis research;*

1 (B) may focus on advancing treatments and
2 developing therapies in paralysis research;

3 (C) may focus on one or more forms of pa-
4 ralysis that result from central nervous system
5 trauma or stroke;

6 (D) may facilitate and enhance the dissemi-
7 nation of clinical and scientific findings; and

8 (E) may replicate the findings of consortia
9 members or other researchers for scientific and
10 translational purposes.

11 (3) COORDINATION OF CONSORTIA; REPORTS.—

12 *The Director may, as appropriate, provide for the co-*
13 *ordination of information among consortia under*
14 *paragraph (1) and ensure regular communication*
15 *among members of the consortia, and may require the*
16 *periodic preparation of reports on the activities of the*
17 *consortia and the submission of the reports to the Di-*
18 *rector.*

19 (4) ORGANIZATION OF CONSORTIA.—*Each con-*
20 *sortium under paragraph (1) may use the facilities of*
21 *a single lead institution, or be formed from several co-*
22 *operating institutions, meeting such requirements as*
23 *may be prescribed by the Director.*

24 (c) PUBLIC INPUT.—*The Director may provide for a*
25 *mechanism to educate and disseminate information on the*

1 *existing and planned programs and research activities of*
 2 *the National Institutes of Health with respect to paralysis*
 3 *and through which the Director can receive comments from*
 4 *the public regarding such programs and activities.*

5 ***TITLE II—PARALYSIS REHABILI-***
 6 ***TATION RESEARCH AND CARE***

7 ***SEC. 201. ACTIVITIES OF THE NATIONAL INSTITUTES OF***
 8 ***HEALTH WITH RESPECT TO RESEARCH WITH***
 9 ***IMPLICATIONS FOR ENHANCING DAILY FUNC-***
 10 ***TION FOR PERSONS WITH PARALYSIS.***

11 *(a) IN GENERAL.—The Director, pursuant to the gen-*
 12 *eral authority of the Director, may make awards of grants*
 13 *to public or private entities to pay all or part of the costs*
 14 *of planning, establishing, improving, and providing basic*
 15 *operating support to multicenter networks of clinical sites*
 16 *that will collaborate to design clinical rehabilitation inter-*
 17 *vention protocols and measures of outcomes on one or more*
 18 *forms of paralysis that result from central nervous system*
 19 *trauma, disorders, or stroke, or any combination of such*
 20 *conditions.*

21 *(b) RESEARCH.—A multicenter network of clinical*
 22 *sites funded through this section may—*

23 *(1) focus on areas of key scientific concern, in-*
 24 *cluding—*

25 *(A) improving functional mobility;*

1 (B) promoting behavioral adaptation to
2 functional losses, especially to prevent secondary
3 complications;

4 (C) assessing the efficacy and outcomes of
5 medical rehabilitation therapies and practices
6 and assisting technologies;

7 (D) developing improved assistive tech-
8 nology to improve function and independence;
9 and

10 (E) understanding whole body system re-
11 sponses to physical impairments, disabilities,
12 and societal and functional limitations; and

13 (2) replicate the findings of network members or
14 other researchers for scientific and translation pur-
15 poses.

16 (c) COORDINATION OF CLINICAL TRIALS NETWORKS;
17 REPORTS.—The Director may, as appropriate, provide for
18 the coordination of information among networks funded
19 through this section and ensure regular communication
20 among members of the networks, and may require the peri-
21 odic preparation of reports on the activities of the networks
22 and submission of reports to the Director.

1 **TITLE III—IMPROVING QUALITY**
2 **OF LIFE FOR PERSONS WITH**
3 **PARALYSIS AND OTHER PHYS-**
4 **ICAL DISABILITIES**

5 **SEC. 301. PROGRAMS TO IMPROVE QUALITY OF LIFE FOR**
6 **PERSONS WITH PARALYSIS AND OTHER PHYS-**
7 **ICAL DISABILITIES.**

8 (a) *IN GENERAL.*—The Secretary of Health and
9 Human Services (in this title referred to as the “Sec-
10 retary”) may study the unique health challenges associated
11 with paralysis and other physical disabilities and carry out
12 projects and interventions to improve the quality of life and
13 long-term health status of persons with paralysis and other
14 physical disabilities. The Secretary may carry out such
15 projects directly and through awards of grants or contracts.

16 (b) *CERTAIN ACTIVITIES.*—Activities under subsection
17 (a) may include—

18 (1) *the development of a national paralysis and*
19 *physical disability quality of life action plan, to pro-*
20 *mote health and wellness in order to enhance full par-*
21 *ticipation, independent living, self-sufficiency, and*
22 *equality of opportunity in partnership with vol-*
23 *untary health agencies focused on paralysis and other*
24 *physical disabilities, to be carried out in coordination*

1 *with the State-based Disability and Health Program*
2 *of the Centers for Disease Control and Prevention;*

3 *(2) support for programs to disseminate infor-*
4 *mation involving care and rehabilitation options and*
5 *quality of life grant programs supportive of commu-*
6 *nity-based programs and support systems for persons*
7 *with paralysis and other physical disabilities;*

8 *(3) in collaboration with other centers and na-*
9 *tional voluntary health agencies, the establishment of*
10 *a population-based database that may be used for lon-*
11 *gitudinal and other research on paralysis and other*
12 *disabling conditions; and*

13 *(4) the replication and translation of best prac-*
14 *tices and the sharing of information across States, as*
15 *well as the development of comprehensive, unique, and*
16 *innovative programs, services, and demonstrations*
17 *within existing State-based disability and health pro-*
18 *grams of the Centers for Disease Control and Preven-*
19 *tion which are designed to support and advance qual-*
20 *ity of life programs for persons living with paralysis*
21 *and other physical disabilities focusing on—*

22 *(A) caregiver education;*

23 *(B) promoting proper nutrition, increasing*
24 *physical activity, and reducing tobacco use;*

1 (C) education and awareness programs for
2 health care providers;

3 (D) prevention of secondary complications;

4 (E) home- and community-based interven-
5 tions;

6 (F) coordinating services and removing bar-
7 riers that prevent full participation and integra-
8 tion into the community; and

9 (G) recognizing the unique needs of under-
10 served populations.

11 (c) GRANTS.—The Secretary may award grants in ac-
12 cordance with the following:

13 (1) To State and local health and disability
14 agencies for the purpose of—

15 (A) establishing a population-based data-
16 base that may be used for longitudinal and other
17 research on paralysis and other disabling condi-
18 tions;

19 (B) developing comprehensive paralysis and
20 other physical disability action plans and activi-
21 ties focused on the items listed in subsection
22 (b)(4);

23 (C) assisting State-based programs in estab-
24 lishing and implementing partnerships and col-
25 laborations that maximize the input and support

1 *of people with paralysis and other physical dis-*
2 *abilities and their constituent organizations;*

3 *(D) coordinating paralysis and physical*
4 *disability activities with existing State-based*
5 *disability and health programs;*

6 *(E) providing education and training op-*
7 *portunities and programs for health professionals*
8 *and allied caregivers; and*

9 *(F) developing, testing, evaluating, and rep-*
10 *licating effective intervention programs to main-*
11 *tain or improve health and quality of life.*

12 *(2) To private health and disability organiza-*
13 *tions for the purpose of—*

14 *(A) disseminating information to the pub-*
15 *lic;*

16 *(B) improving access to services for persons*
17 *living with paralysis and other physical disabil-*
18 *ities and their caregivers;*

19 *(C) testing model intervention programs to*
20 *improve health and quality of life; and*

21 *(D) coordinating existing services with*
22 *State-based disability and health programs.*

23 *(d) COORDINATION OF ACTIVITIES.—The Secretary*
24 *shall ensure that activities under this section are coordi-*

1 *nated as appropriate by the agencies of the Department of*
2 *Health and Human Services.*

3 *(e) AUTHORIZATION OF APPROPRIATIONS.—For the*
4 *purpose of carrying out this section, there is authorized to*
5 *be appropriated \$25,000,000 for each of fiscal years 2008*
6 *through 2011.*

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